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Design for sensitive topics: Empowering the teen

Alison Fichter

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Design for Sensitive Topics

Empowering the Teen

By Alison Fichter

A thesis submitted to the Faculty of the College of Imaging Arts and Sciences
in candidacy for the degree of Master of Fine Arts

May 2003

Rochester Institute of Technology
College of Imaging Arts and Sciences
Graphic Design Department

Design for Sensitive Topics

Empowering the Teen

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Empowering the Teen

By Alison Fichter

Submitted to the Graduate Graphic Design Program, School of Design,
College of Imaging Arts and Sciences, in partial fulfillment of the requirements
for the Master of Fine Arts degree in Graphic Design at the Rochester Institute
of Technology.

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“Life is the first gift, love the second, and understanding the third.”

- Marge Piercy

Dedication

This thesis is dedicated to my loving father, who was diagnosed with Lou Gehrig’s Disease in 1992. Thank you for giving me the strength and courage to undertake and complete this project.

Special Thanks

Special thanks to my thesis advisors Deborah Beardslee, Chris Jackson and Kathy Scott. Special thanks to Karen Folio at Rush Henrietta High School for helping to coordinate the focus group, and to all the students who participated in the project. Special thanks to my fellow graduate students for all of their support and recognition. As always, special thanks to my mom, Ruth Fichter; her love and support have given me the confidence and ambition to succeed in all my endeavors.

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A personal experience inspired the development of this thesis project. In 1992, when the writer was fifteen, her father was diagnosed with ALS (Amyotrophic Lateral Sclerosis), also known as Lou Gehrig's Disease. In the quest to understand the disease, she went to the *World Book Encyclopedia*, a source that had always served well when quick, simple information was needed. However, it failed to provide adequate and comprehensible information, leaving her even more confused and frustrated.

Situation

Ten years later, the problem remains. There still exists a lack of information available for those in crisis. Even though there are more resources available about the disease, few, if any, are targeted at young people. Most of the sources found were for the patients themselves or for the family coping as a unit. Other books offered strictly medical information or tales of courage about living with the disease. No books or sources were specifically for teenagers, but there were a few sources for the young child audience. Web sites were also investigated, however none dealt directly with this topic for the teenage audience.

In response to this situation, a deck of cards was created to provide information in an understandable way to a teenager with a terminally ill parent. The cards include three main sections: *Know*, *Question*, and *Cope*. The *Know* section of the cards provides an explanation of the illness, symptoms, treatment, and medical procedures related to the disease. The *Question* section of the card deck provides answers to the most frequently asked questions concerning the disease. The *Cope* section of the cards describes the various kinds of feelings teens may be experiencing, reassuring them that their feelings are normal. This section also provides other resources that teens may find useful in their quest for information and understanding.

Problem Statement

A teenager, looking to understand a terminal disease, is confronted with sources that are primarily intended for adults or children. The material is presented either in a way which they cannot understand, or which has a childish approach. This often leaves the adolescent more confused and frustrated.

This thesis will develop a set of communication materials for this teenage audience, dealing with a terminally ill parent or loved one. These materials will offer simplified information about the disease called ALS (Lou Gehrig's Disease) and also provide coping methods. Research about effective information design and communication methods will be utilized. This program will serve as a template and could eventually be applied to other terminal diseases.

Goals

The communication materials will answer questions that the teen may have about the illness, its progression, treatment, and the feelings they will encounter with having a terminally ill parent. The following goals reflect the project's focus on information design solutions as applied to the subject of Lou Gehrig's disease, and the teenage audience.

Goals of the Designer:

- To gain a more in-depth understanding of ALS through research
- To gain an understanding of teens coping with loss and eventual death
- To create a structure that will provide information and serve as a tool for conversation between parent and teen
- To use information design principles, communication theory relating to adolescents, and systems design to effectively achieve project goals

Project Goals:

- To serve as an information guide for the intended audience
- To serve as a coping tool for the teenager
- To encourage the reader to explore the subject further

Currently there is insufficient material to help teenagers cope with a terminally ill loved one. Other areas including information design, card game structures, and communication materials for teenagers can provide models to organize content appropriately for the teenage audience. The following precedents support the need for applying design techniques and format decisions toward sensitive topic materials for teenagers.

Precedents for Information Design

Richard Saul Wurman

Information Anxiety 2 and *Medical Access* were two major influences on this thesis project. *Information Anxiety 2* provided the basic foundation around which the project is built. In Chapters Three and Four, Wurman reminds the reader that to effectively communicate information to someone, one must remember what it is like not to understand. The communicator must remember that even though he or she is very familiar with the information, the audience may not have any idea about the subject. In Chapter Seven, Wurman assesses the importance of asking questions as a way of expanding understanding. He stated that questions “help us to assess what we know and what we don’t know” (p 127).

Medical Access provided a precedent for medical information design, demonstrating how to communicate some of the most complicated procedures in an “easy to understand” format. Given the medical nature of the content, *Medical Access* was helpful to the designer in understanding the importance of solving medical information design problems. *Medical Access* was published in 1981 as a response to Wurman’s own experience during a medical examination. This guidebook was developed to provide clear and understandable information for the average patient concerning surgical procedures and diagnostic testing.

Edward Tufte

Edward Tufte has written several books about Information Design and is an internationally recognized scholar in the field. In his book *Visual Explanations*, Tufte writes about the use of parallelism as a means to communicate an idea visually. The concept is to display similar images next to each other so that a comparison can be made. “Spatial parallelism takes advantage of our notable capacity to compare and reason about multiple images that appear simultaneously within our eye span” (Tufte 80).

Images can also be displayed with one like image following another. This concept was used within the card deck in the development of the visuals to aid the understanding of assisted breathing. (See Appendix A for card examples.)

Precedents for Communicating with Teenagers

Brochures

Brochures are a typical format to communicate sensitive topics to the teenage audience. They can provide a range of different formats due to different folds, use of color, and imagery. Many existing brochures were collected. The topics ranged from smoking to sex education to drugs and alcohol. The brochures gathered provided an understanding of how information has been presented to the teenage audience. These brochures were analyzed for content, use of imagery, color, and language.

These brochures were often not visually interesting. They often employed two colors—black and a second color. The second color would be used for the title, subtitles, and occasionally as a background color. Imagery would consist of stock photos of teenagers, a cartoon, or a simple line drawing that would typically appear only on the cover of the brochure. In some cases the imagery would repeat inside the brochure, but only once or twice. Diagrams would occasionally be included to help explain the information.

Simple use of color and imagery provides a straightforward approach to communicating with teenagers. This also creates a product that is fairly inexpensive to produce. Since this resource is typically given away, there is usually a very small budget for producing these kinds of materials.

However, the brochures could have been produced using two colors and a single image by employing techniques that would have made a visually appealing display of information. Some techniques include cropping an image in several different ways, the use of meaningful textures, and using screen values of the second color, possibly in combination with screens of black to increase the overall color palette. When teenagers were asked in casual conversation about their interaction with the brochures, most found them to be uninteresting, and therefore did not bother to read them.

The Teenager's Guide to the Real World

Marshall Brian, the creator of *How Stuff Works* and author of *The Teenager's Guide to the Real World*, is recognized for his ability to communicate complex ideas clearly. The goal of this book is to provide understanding of the adult world so that the teen can make an easy adjustment from adolescence to adulthood. The book was used as a model for how to communicate with the teenage audience.

Marshall Brain's *How Stuff Works* is a full-color, highly visual resource book for those who are searching to understand the way things work around them. Over 1,000 full-color illustrations and photos are used to show step-by-step images of how stuff works. It provides easy-to-understand explanations of the most popular and interesting subject areas, including Technology, Science, Health, Transportation, and more. Sample topics include: How CDs Work, How Car Engines Work, and How Nuclear Radiation and Power Work. The book was published after the success of the web site. One of the most useful features of the web site was the amount of information per page. There was just enough to answer the question, but one could click forward if they wanted further explanation. One of the drawbacks to the book was the amount of information included within the book. The imagery is in full color and fairly complex. To produce something this complex and grand would be expensive, and probably not in the budget of a non-profit organization. However the use of full color photographs, color, and illustrative qualities of the imagery provided visual interest, captivating its target audience. Simplified language and step-by-step explanations of the material made it easy to approach and understand.

Marshall Brian's solutions were an influence on sequencing and content decisions for this thesis project. See p. 35 for additional information.

Precedents for Appropriate Formats

A card deck structure was chosen as the format to present sensitive topic information to the teen audience. This format was chosen because the intimate size allows a small amount of information to be uncovered at a time, so as not to overwhelm the viewer. The card deck can also be used as a tool to promote conversation between parent (or other adult) and teenager. Several card games and other types of decks were collected and analyzed for their use of color, imagery, typography, language, and format.

Popular Teen Card Games

Magic and *Yu-Gi-Oh* were among the popular card games that were used as models for this project. The cards were used to become familiar with what teens were accustomed to seeing and interacting with. They also provided insight to how one might apply color, type, and imagery to a card deck to stimulate the teen audience.

Each card in *Magic* and *Yu-Gi-Oh* has a specific purpose in the game. These decks include illustrations on each of the cards to offer a visual representation of the card's purpose within the game. The illustrations are quite complex and very detailed. This offers visual interest to the target audience. Each of the game cards also includes a title and a brief description of the card's purpose.

Illustrations were included in *ALS: An Informational Card Deck* to provide visual interest to the viewer as well as offer a visual connection to the information being communicated to the viewer. These cards were connected to each other through a flow of information. In order to continue the flow of information, the same imagery was used on cards as a quiet way of connecting ideas and information. Each of the cards also included a title for the card, and information on the card was kept concise and to the point.

Other Card Decks

Other card games and decks such as *Wheedle*, *Truth or Dare*, and *The Creative Whack Pack* were also used as models for this project. *Wheedle* was a model for its use of various colors and graphics within the card deck as a way of unifying the deck, but also to create separate distinct sections in the deck. *Truth or Dare*, used symbols and color as a means to separate the deck into sections.

Although *Creative Whack Pack* is not a game, rather a tool for brainstorming, and is intended for an adult audience, it still provided insight into how card deck structure and graphic design decisions can be used to organize content and be visually interesting. This deck was very flexible in its use. Each card could stand on its own or the cards could be used together. This flexibility provided several different approaches to brainstorming or solving a problem. The cards were divided into four categories. Color coding was used to group the cards. A numbering system was also used to organize and identify the cards.

Research for this project involved the exploration of ALS information, grieving among teens, historic precedents of information design, color theory research, and card deck structures. In addition, a focus group of teens was formed through a local high school. These teens participated in two surveys for the project. Another area of research analyzed existing material that provides ALS information.

Library Research

Library research was conducted in the areas of graphic design, psychology of grieving teens, and ALS information.

Graphic Design

In addition to research related to ALS content, research was conducted in the area of graphic design. Information design icons such as Will Burtin, Ladislav Sutnar, Edward Tufte, and Richard Saul Wurman provided examples of enhancing the accessibility of information.

Will Burtin made a tremendous contribution to the graphic visualization of scientific processes. He believed that the audience is the most important consideration of the designer. Burtin believed that effective design could be evaluated by the “emotional, physical, and intellectual” responses of the audience to the information (Meggs 311).

Ladislav Sutnar developed a philosophy regarding the structuring of information in a logical manner. Information needed to be easy to find, read, understand, and remember. “Flow means the logical sequence of information” (Meggs 313). He used line, shape and color as functional elements to direct the eye as it moved through the information (Meggs 313).

The graphic design influence of Edward Tufte and Richard Saul Wurman were discussed earlier in the Precedents section of the thesis documentation. These two designers were influential in providing information design models used in this study. See p. 8 for additional detail.

Psychology of Grieving Teens

In order to create an effective deck, it was important to understand the emotional needs of a teenager when faced with a terminally ill parent. Although there were none that dealt directly with a parent with ALS, there were some books about a parent having cancer. *When a Parent has Cancer* provided great insight into the psyche of the typical adolescent. At this stage in their lives, teenagers begin to separate from their families and test their independence. In regard to dealing with a parent's serious illness, the teenaged child sits on the fence between childhood and adult. Sometimes they will have the exact same needs as their younger counterparts. Other times they may seem to fit more into the adult category, and sometimes they are dealing with feelings and problems unique to the teen age group (Harpham 101).

Dr. Harpham stresses the importance of communicating openly and honestly with the teenager. Teens are much more sensitive to half truths and lies. Once teens feel that they have been lied to, it is a difficult task to earn that trust back again. They are more likely to pass off the parent as a liar, and not trust anything they say from then on (Harpham 106).

Another great resource that provided information regarding the psychology of teens was *How to Help Children Through a Parent's Serious Illness* by Kathleen McCue. Her book explains the importance of providing extensive information to the teen audience. "Most adolescents seem to need an enormous amount of information: they want to be treated pretty much as adults. Not only will they want the basic information of the diagnosis, but they'll ask as well for technical terminology, statistical information on survival rates, the depth of their questioning may astonish you. And you must not duck" (McCue 16).

Some of the other books provided information about grieving after the death of someone close. These books were useful in discovering the types of feelings which follow the death of a parent with a long illness. While the information was useful in understanding a teen's grieving period, it did not provide any coping strategies to be used while the parent was ill.

ALS Books and Web sites

Books containing information about ALS were difficult to locate. Few books were intended for the average person. A good portion were medical texts that were very expensive and must be special ordered. Bookstores had little to offer, so all of the reference materials were gathered through interlibrary loan. These texts provided medical explanations, treatments, and ALS patient support. These texts were very dense, and sometimes very difficult to read and comprehend, even for an adult. Some of the medical terminology was difficult to understand. The texts used for content information were intended for adults afflicted with the disease and their families.

These texts were useful in gathering content information for *ALS: An Informational Card Deck*, but they lacked visual interest, were dense, overwhelming to read, and did not speak to the teenage audience. These books did not contain any information about how to cope with the diagnosis of ALS. One would have to find other sources for this kind of information.

Books and web sites were used for content research, as well as a means to understand approaches to the structure and organization of information. Attention to audience considerations and type of content in these sources was useful in understanding who primary target audiences were and what type of information was presented to them. The following two matrices were developed, one for books and the other for web sites, to identify which target audiences had not been addressed as well as where gaps may exist in available materials.

Research

Comparative matrix created to organize research from ALS books and web sites.

ALS Books (Titles)	Content			General Audience			Specific Audience		
	Define ALS	Extensive Medical Information	Inspiration	Child	Teenage	Adult	Medical Professional	Patient	Caregiver
A Booklet for Young People	•			•					•
Grandpa, what is ALS?	•			•					•
Journeys with ALS	•		•			•		•	•
Tuesday's With Morrie			•			•		•	•
Morrie in His Own Words			•			•		•	•
Amyotrophic Lateral Sclerosis	•	•				•	•		
Amyotrophic Lateral Sclerosis A Guide for Patients and Fam.	•	•				•	•	•	•
ALS 1996 and Beyond: New Hopes and Challenges	•	•				•			
Motor Neuron Disease		•				•		•	•

Web sites	Content Covered								Point of View	Audience			
	Define ALS	Coping Info	Resources Info	Forum Chat Room	Support Group Info	FAQ ALS	ALS Research	Personal Story		Teenage	Adult	Patient	Caregiver
kylehahn.com	•		•	•		•	•	•			•	•	•
alslinks.com	•	•	•		•						•	•	•
also.org	•				•	•	•				•	•	•
alsnetwork.com	•		•		•		•	•			•	•	•
alscecilneth.net	•	•	•					•			•	•	•
als.ca	•	•	•	•		•	•				•	•	•
alssurvivalguide.com	•	•		•			•				•	•	•

Theses matrices revealed that there are no books or web sites that speak directly to the teenage audience. The kind of information provided by books differed from the type of information provided by web sites. The matrices were developed to identify the different types of information covered in each resource. Books had one of two purposes: to provide medical information to the patient, caregiver, or medical professional, or to offer inspirational help to those struggling with the disease and their families.

Web sites covered a wider range of topics. They addressed other audience needs, such as support group information, current research in the field, and personal stories. The web sites also offered more concise descriptions of the medical information but occasionally lacked needed detail.

Focus Group

A group of students from Rush Henrietta High School were asked to participate in this project as a means of gathering research and feedback. The students participated in a series of surveys. The first survey gathered information about the type of content to include in the card deck. Students were asked a series of content questions about to whom they would turn for information and what kind of information they would seek. They were also asked questions about design decisions, such as color and the use of imagery. In addition, students were asked to draw a representation of how they would feel if they had a terminally ill parent. Some of the imagery was later incorporated within the cards to offer visual interest and connection to the teens through peer artwork.

During this focus group process the teens were asked to list the types of activities they were involved in. This provided insight to how teens like to spend their time and what activities they like to participate in. Most teens responded that they enjoyed playing sports, listening to or playing music, watching movies with friends, and just hanging out.

First page of a two page survey that was passed out to the students at Rush Henrietta High School. See Appendix B for completed surveys from students.

Alison Fichter
MFA Thesis Project
Focus Group Survey
2/28/03

Content Questions

If your parent were terminally ill, and you wanted more information about the disease, where would you go to find the information?

Medical books journals/magazines Web site Pamphlet Encyclopedia Video

Other _____

Who would you ask for information?

Parent Doctor Nurse Counselor Librarian Teacher Friend

Other relative Sibling Other _____

What kind of information would you seek?

facts about the disease medical research medical equipment support group info

how to cope frequently asked questions Other _____

Would you want to talk to other teenagers going through a similar situation?

Yes No Maybe I don't know

Would you consider going to a Teen Peer Support Group?

Yes No Maybe I don't know

Do you think you would talk about a parents' illness with your friends?

Yes No Maybe I don't know

Would you like to read/hear about information from a personal story/ personal point of view, or would you prefer information to be presented in a more formal way?

What sort of involvements/activities/hobbies do you like to partake in? Please list.

What kind of activities do you like to do with others?

What kind of activities do you like to do by yourself?

Second page of the survey
completed by students at Rush
Henrietta High School.

Design Questions				
What color(s) make you feel calm/ peaceful/ at ease?				
What color(s) make you feel anxious/ stressed/ upset?				
Do you relate specific colors to medical information? If yes, what colors do you think of?				
Would images be useful/helpful to make the information easier to see and understand? If yes, can you think of what kind of imagery you would best relate to?				
Photographs	Illustrations	diagrams	charts or graphs	pictograms/ symbols/ icons
Other _____				
Besides a pamphlet, how might this information be presented in a useful way?				
Some kind of card deck	Book bound on both sides and pages flip from the middle	Some kind of puzzle		
On a 3-D cube	Other _____			
Personal Information				
Age _____				
Sex	Male	Female		
Have you ever known anyone with a terminal illness?				
Yes	No			

A total of eleven surveys were completed. A matrix was created to condense and organize the results of the surveys. The questions were arranged along the y-axis, and answers were arranged along the x-axis. In the intersection, a number was placed corresponding to the number of people that circled that answer on their survey. Students were allowed to circle all answers that applied. In one instance, students were asked to list colors they associated with feeling calm and colors that produced feelings of anxiety. No color suggestions were provided for this question, to see if there were common answers among the teens. Surprisingly, the students agreed on a handful of colors that they associated with these feelings. All the colors that the students mentioned were listed along the top axis.

Organizing this information with the use of a matrix revealed a consensus of what should be included in the card deck. Teens expressed interest in knowing medical facts, research, answers to frequently asked questions, and ways to cope with the disease. It also provided a guideline for the types of color and imagery the teens would most respond to.

Research

Results of the survey that was taken by the focus group at Rush Henrietta High School.

If your parent were terminally ill, and you wanted more information about the disease, where would you go to find the information?	Medical books	Journals/ Magazines	Web site	Pamphlet	Encyclopedia	Video				
	8	0	9	2	2	2				
Who would you ask for information?	Parent	Doctor	Nurse	Counselor	Librarian	Teacher	Friend	Other relative	Sibling	
	2	10	5	0	0	3	1	1	1	
What kind of information would you seek?	facts about the disease	medical equipment	medical research	how to cope	frequently asked questions	support group info	Other			
	8	1	5	5	4	1	everything			
Would you want to talk to other teenagers going through a similar situation?	Yes	No	Maybe	I don't know						
	7	2	1	1						
Would you consider going to a Teen Peer Support Group ?	Yes	No	Maybe	I don't know						
	1	5	5	0						
Do you think you would talk about a parents' illness with your friends?	Yes	No	Maybe	I don't know						
	3	2	6	0						
Would you like to read/hear about information from a personal story / personal point of view, or would you prefer information to be presented in a more formal way?	personal story / personal point	formal way	both							
	5	2	4							

What color(s) make you feel calm/peaceful/at ease?	Green	Blue	light blue	Purple	Earth tones	Pale yellow	Red	Pale grey	Silver	White
	3	5	3	3	3	2	1	1	1	1
What color(s) make you feel anxious/stressed/upset?	Red	Black	Orange	Bright Yellow	Pink	grey				
	7	5	3	3	2	1				
Do you relate specific colors to medical information? If yes, what colors do you think of?	Red	Blue	White	Orange	Black					
	3	3	2	1	1					
Would images be useful/helpful to make the information easier to see and understand? If yes, can you think of what kind of imagery you would best relate to?	Photographs	Illustration	Diagrams	Charts/ graphs	Pictograms/ Symbols/ Icons					
	9	4	7	5	4					
Besides a pamphlet, how might this information be presented in a useful way?	Card Deck	Double bound book	puzzle	3-D cube	other					
	1	6	3	3	lecture/ play production					
Age:	15	16	17							
	2	6	3							
Sex:	male	female								
	3	8								
Have you ever known anyone with a terminal illness?	Yes	no								
	11	0								

Teen Magazines

Teens are exposed to many kinds of visual influences, such as television, movies, newspapers, advertisements, and magazines. Based on the feedback from the focus group about how they like to spend their time, several popular magazines that specialize in sports, entertainment (TV, movies), music, and fashion were collected and analyzed for their use of color, type, imagery, and use of language. This provided some direction for how to visually connect with the target audience.

Visually interesting magazine pages and spreads were selected from popular teen magazines, such as *Teen Vogue*, *Entertainment*, and *Snowboarding*. The most visually interesting aspects of each example were noted in terms of use of color, type, imagery, and layout. The list compiled at the end of the exercise was used as a means for experimenting with visual elements that teens relate to.

Selected magazine spreads displayed for an analysis of form, color, typography, and imagery.



Research

The magazines used colored type to highlight key words, phrases and titles of articles. This provided a typographic hierarchy to the page as well as visual interest. All different types of imagery were used, including photographs, illustrations, cartoons, graphics and geometric shapes. The type of imagery selected for a page depended on the article it accompanied and its purpose. More laid back articles included bright colors and the use of cartoons. This created a fun atmosphere for the article. More serious topics were accompanied with photographs or realistic imagery, creating a more serious tone.



Solid colored geometric shapes were used as a color field to place and isolate sections of text from one another. This technique was used when the text was not part of one continuous story, but several thoughts or phrases combined on one page. The readers could pick and choose where they wanted to read first.



Card Decks

All of the card games and decks that were collected for this project were analyzed and compared. The front and back of the cards were assessed along with their packaging. Details about the cards were noted, including size, color, use of graphics or imagery, type, and any indication of sequencing or order.



A common size and proportion were found among the card games, 2.5 x 3.25. That information was used to determine the size and proportion for developing *ALS: An Informational Card Deck*. The most popular card games among teenagers currently are *Magic* and *Yu-Gi-Oh*. These cards used a different illustration on each card as a means to convey the meaning of the card. The illustrations are quite complex and very detailed. This offers visual interest to the target audience. The cards in each game also included a title and a brief description of the card's purpose.



Image of *Magic* card game

Truth or Dare had two different sections to the deck: a question section and a dare section. Punctuation was used on the back of the card as a means to represent the difference between the sections. The deck also used different colors to help distinguish the cards and the sections they belonged to.



Image of *Truth or Dare* card game

The Creative Whack Pack was noted for its use of color and numbers. This deck has a different purpose than the other decks examined during this research project. This deck is intended for an adult audience and is a tool used for brainstorming ideas and solutions. The cards for this deck were also categorized into four sections. They could be used individually or together as a whole section. The numbers helped to keep track of the cards. The deck also came with a booklet that served as a reference guide. It provided suggestions on how to use *The Creative Whack Pack* and the categories in which the cards are grouped.

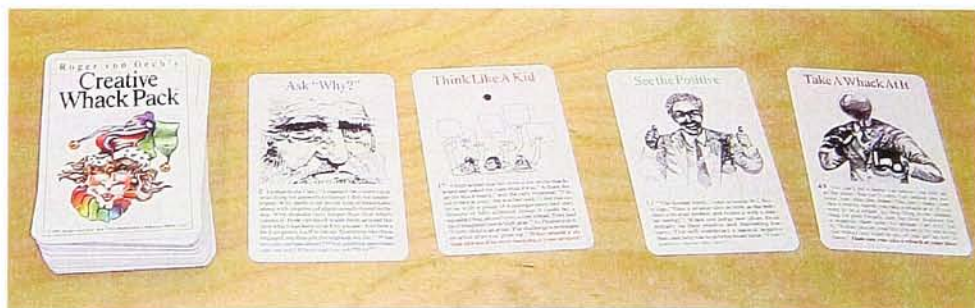


Image of *The Creative Whack Pack*

Multiple Intelligences

Thomas Armstrong's book, *Multiple Intelligences in the Classroom* uses Howard Gardner's Theory of Multiple Intelligences as a tool to help children learn. Gardner believed that there are at least seven different intelligences: Linguistic, Logical, Spatial, Bodily-Kinesthetic, Musical, Intrapersonal, and Interpersonal. He theorized that all people have these intelligences, but that some intelligences were more dominant than others which varied from person to person. Armstrong theorizes that by tapping into one's dominant intelligence, and presenting information to them in a form that relates to his or her dominant intelligence, they will learn things easier.

Below is a matrix that Armstrong developed describing seven kinds of learning styles. The y-axis lists seven different intelligences. The x-axis labels are *Think*, *Love*, and *Need*. *Think* refers to how a child thinks (in words, images, by reasoning, etc.) according to each intelligence. *Love* explains how children with that dominant intelligence prefers to spend their time. *Need* lists activities and objects that help the child to learn through the use of their dominant intelligence.

Children who are Strongly:	Think	Love	Need
Linguistic	in words	reading, writing, telling stories, playing word games, etc.	books, tapes, writing tools, paper, diaries, dialogue, discussion, debate, stories, etc.
Logical-Mathematical	by reasoning	experimenting, questioning, figuring out logical puzzles, calculating, etc.	things to explore and think about, science materials, trips to the science museum and planetarium, etc.
Spatial	in images and pictures	designing, drawing, visualizing, doodling, etc.	art, LEGO's video, movies, slides, imagination games, mazes, puzzles, illustrated books, etc.
Bodily-Kinesthetic	through somatic sensations	dancing, running, jumping, building, touching, gesturing, etc.	role play, drama, movement, things to build, sports and physical games, hands on learning, etc.
Musical	via rhythms and melodies	singing, whistling, humming, tapping feet and hands, listening, etc.	sing-along time, trips to concerts, music playing at home and school, musical instruments, etc.
Interpersonal	by bouncing ideas off other people	leading, organizing, relating, manipulating, mediating, partying, etc.	friends, group games, social gatherings, community events, clubs, mentors/apprenticeships, etc.
Intrapersonal	deeply inside of themselves	setting goals, meditating, dreaming, being quiet, planning, etc.	secret places, time alone, self-paced projects, choices, etc.

Comparative matrices were used to organize and condense research to make it more accessible. Generative matrices were used to develop ideas that would connect research to the goals of the project. The matrices below are two examples of the generative matrices that were developed for this project. Audience considerations played a large role in the creation of this thesis. The first matrix dealt with basic attributes of an audience including age, gender, culture, and personality. The x-axis of this matrix dealt with design considerations.

Design Considerations								
	Color	Typography	Imagery	Compositional Space	Language	Legibility	Accessibility	Navigation
Audience Considerations								
Age								
Gender								
Culture								
Personality Considerations								
Introvert								
Extrovert								

An index card was used for each intersection of this matrix. These cards were used for the compilation of ideas that were used to develop sketches of the design application. This method provided flexibility. Often more than one card was developed for each intersection. Some examples of index cards created from the matrix above are shown on the next page.

Synthesis

This card, *Age/Color*, focuses on developing ideas about what kinds of colors teens would best relate to. It was noted on the index card that multiple colors would help create a visually interesting application.

age/color

age 14-18 (13-19) - teens

What colors do they relate to?

- Bright colors
fun, energetic
multicolored — not boring or dull
- fun, whimsical, happy, glowing, hot, Engaging, friendly, loved
- kitsy, cheap, bad, trendy, tacky
- sky, blue, calming, cool, constant, true, faithful
- dependable, happy, useful, tranquil
- credible, handsome, basic, strong, dependable, secure, professional

The *Introvert/Accessibility* index card focus on how information should be presented to the audience. The index card suggests that a compact printed piece would allow the teen to take the object to a quiet place to absorb the information.

Accessibility / Introvert

introvert maybe more likely to seek out information on one's own.

Printed material would allow for quiet time to take the information in, in a private/quiet area, especially if one does not have a computer, and may not feel comfortable looking up such information at school or in a public library.

- Important that printed material be available and/or distributed at health offices at school and/or community hospital, health center

The *Age/Typography* index card explores different options for typographic solutions in regards to the age of the audience. The target audience for this thesis is teenagers. It would be appropriate to use a type face that is modern as opposed to a more traditional typeface. Futura and Univers were two type families that fit this description.

age / typography

young audience > more hip > modern

- sans serif type
- have good eyesight > type size is not an issue — although some teens may wear glasses.
- Futura — looks modern
- Univers — easier to read.

Synthesis

The *Age/Imagery* index card explores some options for the type of imagery that could be included on the card. A younger teen audience may prefer a more cartoon approach, while an older audience may relate better to more photo-realistic imagery.

Age/Imagery

teen -
younger audience > more cartoon
2D characters

older audience relate more to photos
showing persons like themselves
in the images - can see themselves
relating

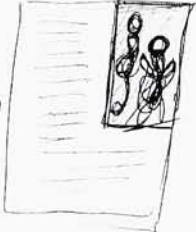
The *Extrovert/Compositional Space* index card suggests using the edges and close croppings of an image to provide a bolder use of the compositional space.

Compositional Space / Extrovert

Bolder use of space

More aware of the use of the edges as a cropping tool

Free, less controlled and predictable use of compositional space, but still using grid structure to organize information effectively



Synthesis

The matrix below also addresses audience considerations. This matrix focuses on generating ideas related to audience intelligences and content information. Gardner's model for multiple intelligences was an influence on the development of this matrix (see page 24 for full explanation). Audience intelligence and content were used as axis labels. Ideas were generated to show how one might present information that would tap into one's dominant intelligence.

Audience Intelligences	Defining ALS	Coping Methods	Resources Print/Web	Support Group Information	Forum/chat Room	Medical Research	Frequently Asked Questions
Linguistic Intelligence							
Logical-Mathematical Intelligence							
Spatial Intelligence							
Bodily-Kinesthetic Intelligence							
Musical Intelligence							
Interpersonal Intelligence							
Intrapersonal Intelligence							

An index card was also developed for each intersection of this matrix. The next page provides sample index cards that were generated. Ideas from these cards played a key role in developing sketches for the design application.

Synthesis

The Logical Intelligence/FAQ index card proposes using a logical puzzle to uncover the information instead presenting it in a straight forward manner.

FAQ / Logical think by reasoning

have ~~the~~ the Questions listed, with
the answers following them, but
see how the order of the questions can
be changed. maybe there is
a way to uncover ~~into~~ the information
in such a way to promote reasoning -
getting them to think a little on their
own, and put the puzzle pieces

The Spatial Intelligence/Defining ALS index card suggests using diagrams to help explain aspects of the illness.

Defining ALS / Spatial Intelligence

think in images and pictures.

- having a diagram to help explain
how the illness affects neurons
and the muscles.

relates to drawing & visualization.

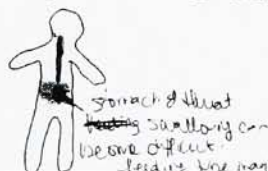
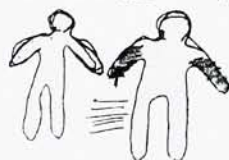
The Bodily Kinetic Intelligence/Defining ALS index card suggests the use interactive diagrams or building small three-dimensional human body models to help a teen learn about the disease and its affects on the body.

Defining ALS / Bodily Kinesthetic

- think through somatic sensations

- hands on learning

maybe diagram ~~is~~ on web could
be interactive. clicking on parts of
the body could show how the
disease affects those areas



stomach & throat
swallowing can
become difficult
leading to maybe needing



leg
may need walker
and crutches
wheelchair to
get around.

Synthesis

The *Bodily Kinetic Intelligence* / FAQ index card suggests the use of pull tabs or flip tabs to offer interactivity to the cards. This would create a physical sensation when uncovering information.

FAQ / Bodily - Kinesthetic
thinks through somatic sensations

- Booklet could have pull tabs or ~~flap~~ tabs that flip open to reveal the answer to a question making the user interactive ~~that~~ with the Booklet.
- this would ~~also~~ create a physical sensation when discovering new information.




(e like opening a door)


The *Spatial Intelligence* / Resources suggests the use of icons to denote the type of resource being listed in the resource section of the card deck. For example an icon of a mouse could be used to represent an internet resource. This idea was employed to give a visual representation to each section of the card deck through the use of punctuation.

Resources / Spatial
thinks in images and pictures

- ^{imagery} icons being used to denote ~~is~~ what type of resources are being listed



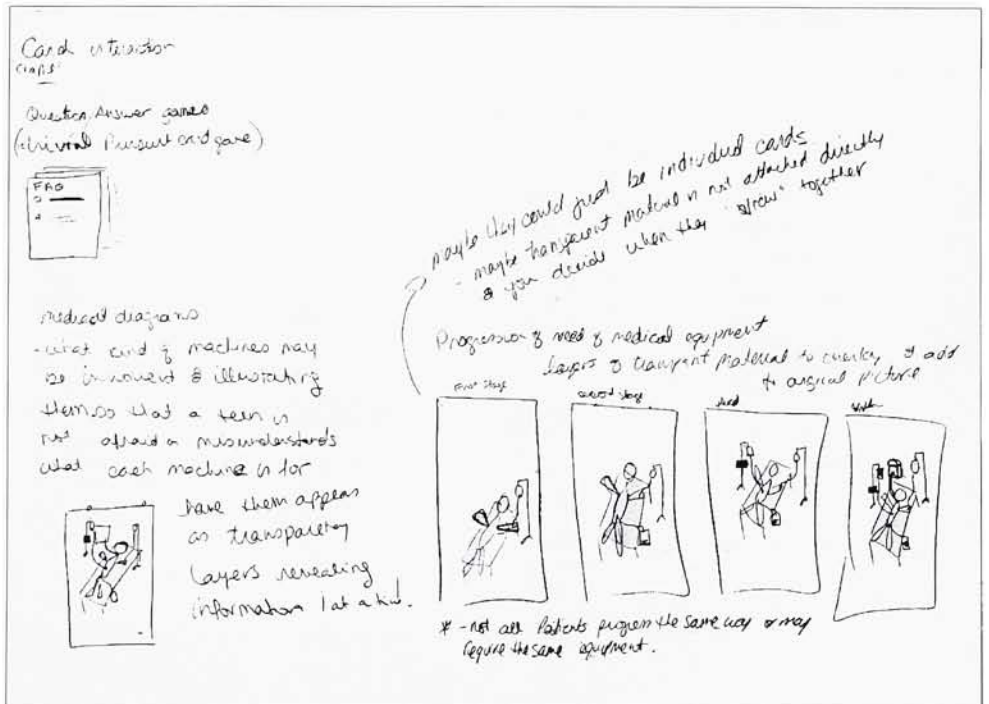
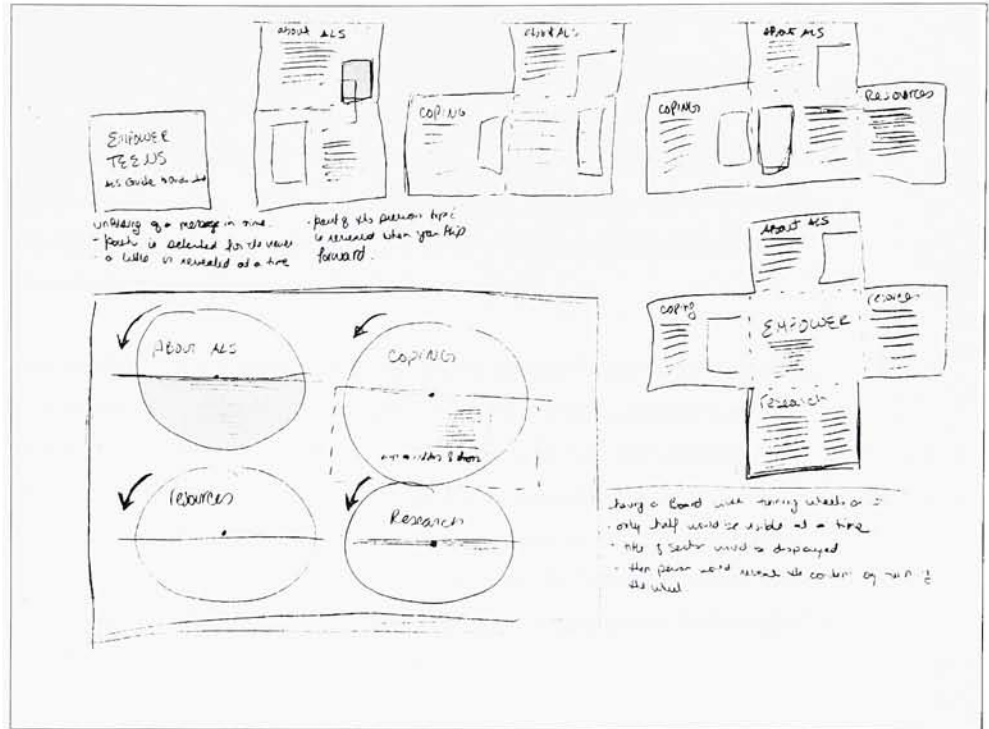
Books



Internet

Ideation

Another example of sketches developed from the mind map.



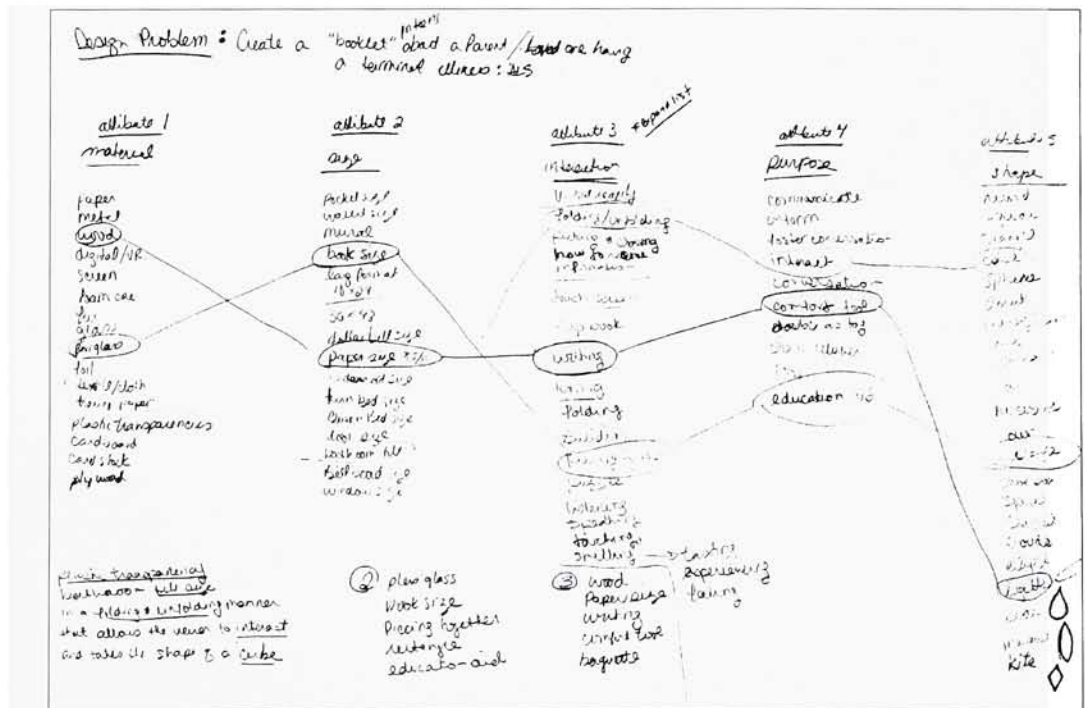
Ideation

Forced Juxtaposition

Forced juxtaposition is another brainstorming method used for generating ideas and making connections. This method encourages or “forces” one to make connections between attributes of a subject that he or she may not otherwise have done. The exercise began by first stating the design problem: Create a communication program for teens, offering information about a parent’s terminal illness.

Five attributes of a potential communication program were listed: material, size, interaction, purpose, and shape. Under each general attribute, a list of specific possibilities was created. One word was randomly selected from each completed list, and these words served as inspiration for a particular brainstorming direction. A word grouping of metal, mural, flip book, stress reliever, and ellipse would possibly generate concept directions and sketches that are quite different from a word grouping of tracing paper, dollar bill size, building up, double as a toy, and triangle.

Below is a visual example of the attributes list and how the three word groupings were randomly selected (see the following page for word groupings).



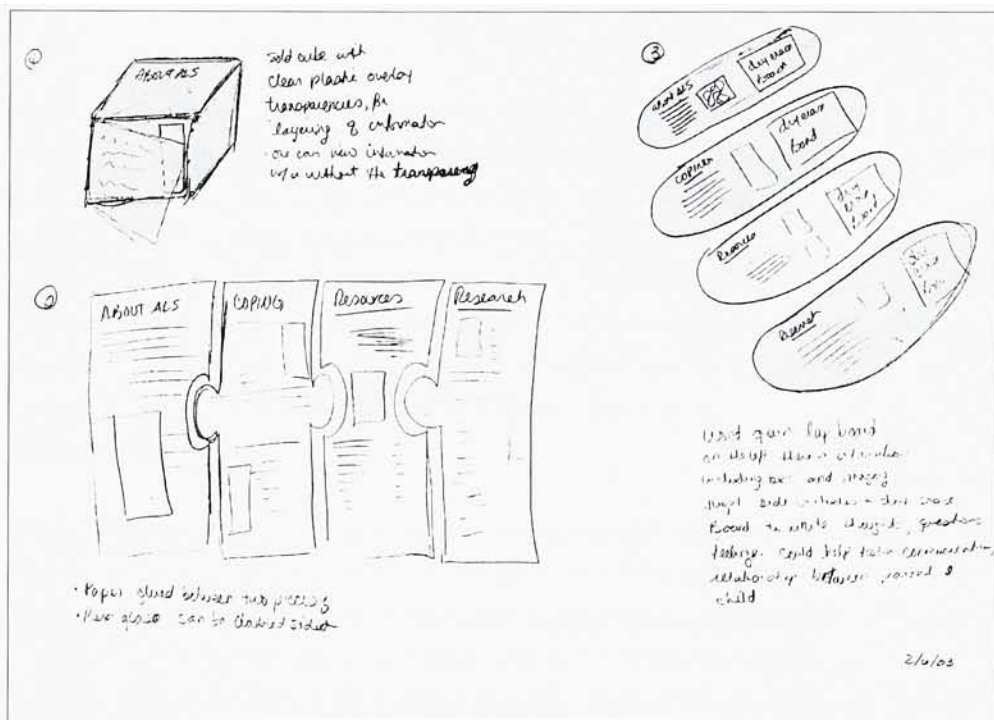
Ideation

The first word grouping created from this method was: plastic transparency, bathroom tile size, folding and unfolding, viewer interaction, and cube shape.

The second word grouping was plexiglass, booksize, piecing together, rectangle, and education aid. The third selection of words include: wood, wallet size, writing, stress reliever tool, and baguette shape.

The designer creates sketches based on an interpretation of the word groupings.

Below is a visual example of the sketches that were created from the word groupings listed above.



After the format of the application had been determined to be a card deck, content and design were considered. Synthesis of the research from the focus group and other sources determined many aspects of the content and design decisions.

Content

Focus group surveys identified the type of information the teen would seek if they had a terminally ill parent or loved one. Teens seemed most interested in knowing the facts about the disease, the answers to frequently asked questions about the disease, and ways to cope with this life change. The best solution seemed to be dividing the card deck into three sections: *Know, Question, and Cope*.

Results from the book and web site research matrices also determined the type of content to be included. *ALS: An Informational Card Deck* combined information categories found in books and web sites to offer a more comprehensive tool for learning. Books were typically filled with medical information and facts. Web sites offered more comprehensive information about how to emotionally deal with the disease. Web sites are also easier to update, and therefore could include current research being done in the field. Books did not include information that would be obsolete in a short period of time.

Marshall Brian's approach to organizing and displaying information was employed for arranging some of the information on the thesis application, *ALS: An Informational Card Deck*. In some cases the content was explained in a more scientific way to honor the teen's desire for adult scientific information. However, a simplified version of the information was presented on the following card, giving the viewer a second explanation. In another example from the card deck, a process of different options for treatment were explained. All of the ideas could not be included on one card. To solve the problem, an introductory card directed the viewer to all the other cards that contained the information.

Implementation

Know

This section of the card deck provides medical facts about ALS. It defines the illness, its effects on the body, the symptoms, life support equipment and procedures, and current research to find treatment and a cure. The content is arranged into three subsections. The first section includes basic information about the disease. The second part of this section is the proactive response to the disease, and includes treatment and exercises. The third part of this section includes the more serious invasive options for treatment, such as eating and breathing assistance. Typically the first thing people want to know is what the disease is. By understanding the nature of the illness through this section of cards, teens can prepare themselves for what is to come.

Question

This section of the deck provides brief, but descriptive answers to the most frequently asked questions about the disease. The questions are laid out in a table of contents, allowing the viewer to decide which questions they would like the answers to first. This section of the deck is broken into four subsections. The questions at the beginning of this section deal mainly with defining what the illness is, what its causes are, how it is diagnosed, and who it affects. The second subset pertains to questions about treatment and cures. The third subsection answers questions about how the disease affects the body. The final questions offer insight into the history of the disease, including terminology and famous people who have had the illness.

Cope

This section contains information that may help the teenager expect and cope with various kinds of feelings due to a parent having ALS. The goal of the *Cope* section is to offer information about support groups, and to encourage teens to ask questions and talk about their feelings with someone they trust. This section can be separated in two subset sections. The first subsection includes information about the kinds of feelings a teen may be experiencing. This section provides emotional support. The second subsection includes book resources that teens may find beneficial in understanding and coping with a parent's terminal illness.

Design

Design considerations for the card deck included color, typography, imagery and format. This card deck was created with a teenage audience in mind. The cards needed to be visually appealing and respectful of the sensitive subject matter. The design was influenced by the research done about teen interest, card decks, and magazines (see pages 16-23).

Format

The cards were designed to share small amounts of information at a time, so as not to overwhelm the viewer. The card deck can also be used as a tool to promote conversation between parent (or other adult) and teenager.

The size and proportion of the card deck were determined from studying popular card games and decks (see pages 22-23). A common size, 2.5 x 3.25 inches was noted. The cards were enlarged proportionally until a final size of 4.25 x 6 inches was reached. This proportion was used because it is one that teens are familiar with. The size was increased to accommodate more information on each individual card.

A Table of Contents was used to introduce each section of the card deck. All the cards were numbered and given a title. This would allow the viewer to easily locate the information they were seeking. A circular tab was incorporated on the Table of Contents card as a way to indicate the beginning of each section. This shape is intended to provide a more calming appearance to the deck, as opposed to something with a sharp edge or corner.

Color

Color theory research and feedback from the focus group determined a color palette (see following page for color theory). The focus group noted that they found blues and purples to have a calming effect. These colors were used to promote a soothing effect. Reds, yellows, and other bright colors were noted for causing stress and anxiety. The researcher avoided using these colors because of the negative effect the focus group perceived these colors to have.

Implementation

Color theory research provided insight into how colors communicate to a viewer. Blue is the color of the sea and sky. It is often associated with stability and depth and symbolizes confidence, wisdom, trust, intelligence, and truth. (Eiseman, p 39)

Blue is considered beneficial to the mind and body. It is strongly associated with tranquility and calmness. Light blue is associated with health, healing, tranquility, and understanding (Color Wheel Pro). Based on this research, it seemed appropriate to use a light blue for the *Know* section of the card deck.

Purple combines the stability of blue and the energy of red. Purple is associated with royalty. It symbolizes power, nobility, luxury, and ambition. Purple is associated with wisdom, dignity, and independence (Eiseman, p 47).

Purple's close connection with blue and its tranquil quality made it a good choice for the *Question* section of the *ALS: An Informational Card Deck*. Its connection with power, wisdom, and dignity are appropriate for the content that is included in this section. Asking questions gives wisdom. With wisdom comes power.

Orange combines the energy of red and the happiness of yellow. It is associated with sunshine and joy, and symbolizes determination, success, encouragement, and happiness (Eiseman, p 27, 63).

Orange increases the oxygen supply to the brain, producing an exhilarating effect and stimulating mental activity. Orange is also very accepted among young people. (Color Wheel Pro) A soft orange, or peach, was used for the *Cope* section for its nurturing and cheerful quality.

Typeface

The geometry of the typeface Futura mirrored the geometry in the cards and tabs. The pure geometry of the typeface added a more modern appearance to each card to ensure a connection with the teen audience. A slightly widened line spacing was used to make the cards feel approachable and readable.

Graphic Elements

Punctuation marks were used as icons to represent each section of the cards. This was one way to graphically represent each card and the particular section it belongs to. An exclamation point was used for the *Know* section, a question mark was used for the *Question* section, and a set of quotation marks for the *Cope* section. Quotation marks were selected for the *Cope* section because of their association with conversation. The *Cope* section strongly encourages talking about feelings and offers information about support groups.

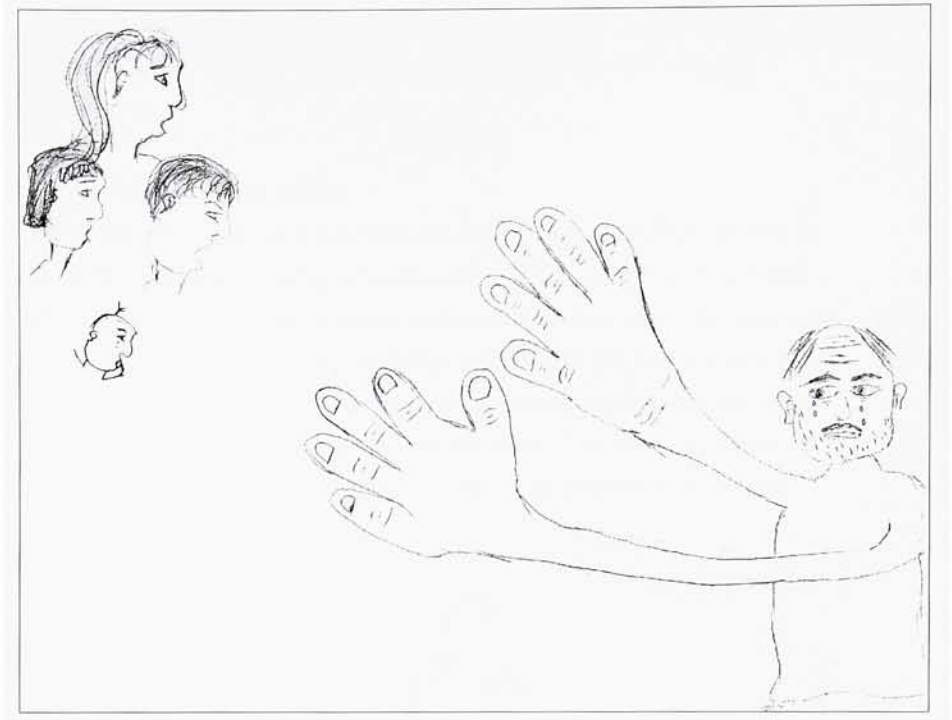
Imagery

Imagery was incorporated into the layout of the cards to increase their visual appeal to the teen audience. Focus group members were asked at the initial meeting to complete a survey. They were also asked to produce drawings that would represent how they might feel if they had a terminally ill parent. Two of the drawings were very powerful in their representation. They were selected as imagery for the project and are shown on the following page.

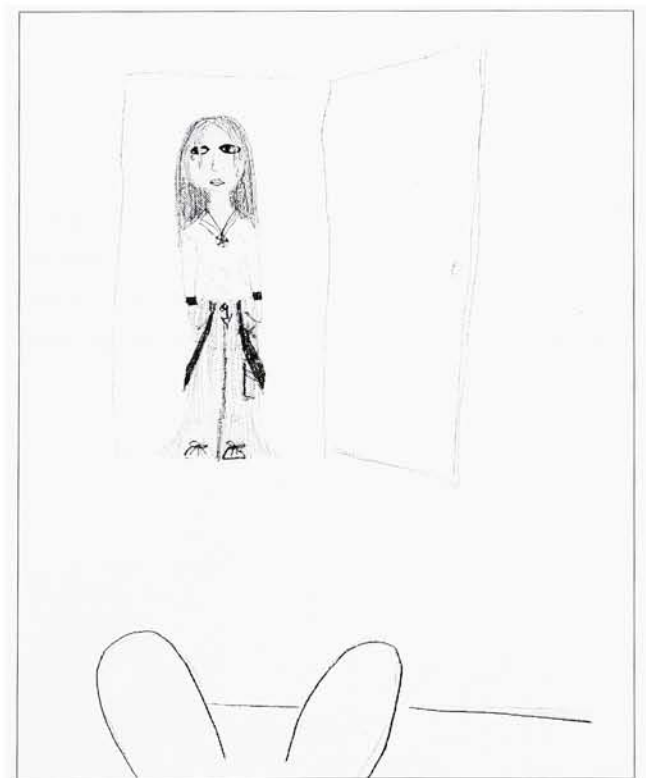
Implementation

Two drawings created by the high school students.

These drawings were used as imagery within the cards.



1. Illustration by Nazan Koksall



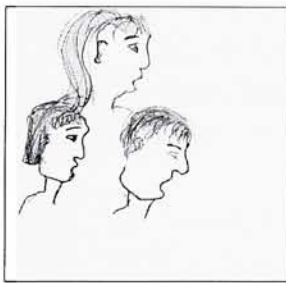
2. Illustration by Dina Katawazi

Implementation

The drawings on the previous page were the two selected to be used as imagery throughout the cards. Different croppings of the image were used for each section.

Imagery for the Know Section

The family part of the image in Drawing 1 was used in the *Know* section of the cards. A second cropping of the images was also used. The three images were used to help distinguish three sections within the cards. The cards with just the family represented are cards that define what the illness is and how it progresses. The second part of this section describes treatment and could be considered the proactive response to the illness. The image included is a cropping of the family with hands reaching out to them from the lower right-hand corner.

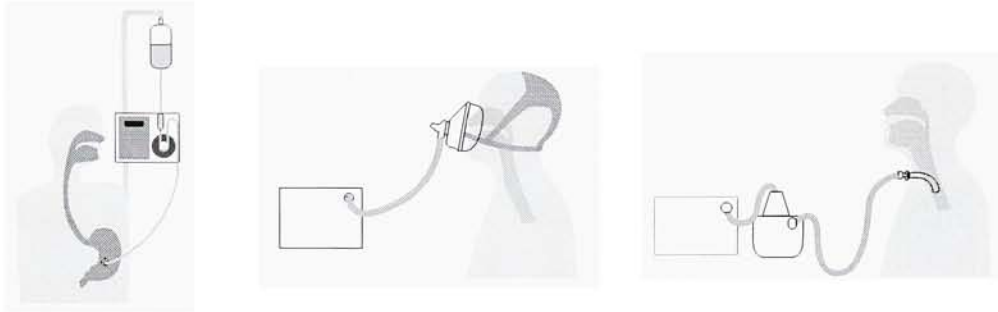


The third section of the card deck is more serious and offers information about invasive treatment responses to the illness. A third cropping of the image was used. In this case, just the image of the hands was used to signal a closer connection to the ill person's decision to partake in these invasive treatments.



Implementation

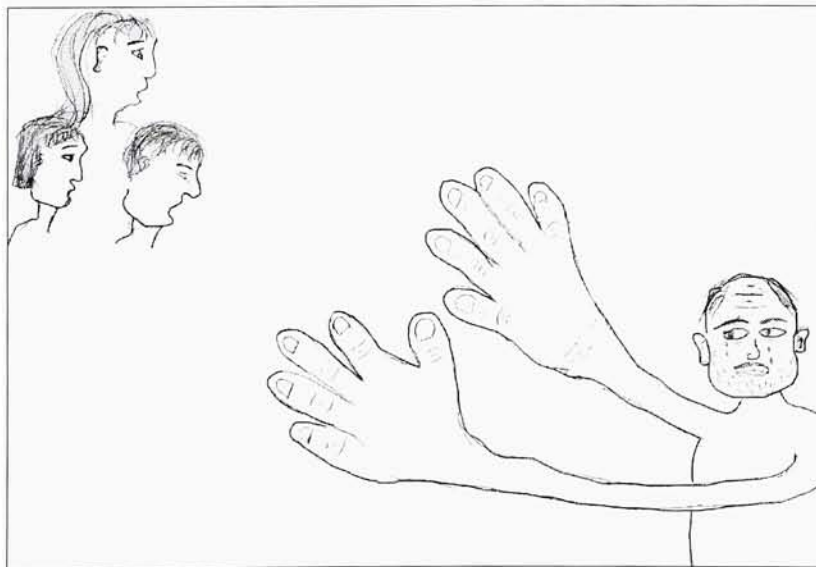
A different type of imagery was also included in this part to help inform the viewer about invasive procedures. Graphic medical illustrations were used to aid the viewer in understanding the material. The illustrations below were used to help explain life support treatments such as assisted eating and breathing.



Imagery for the Question Section

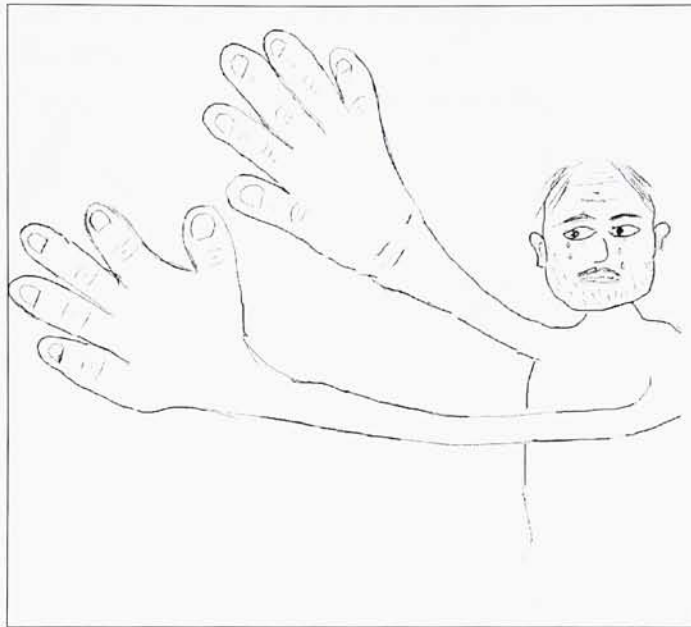
The *Question* section of the cards was separated into four parts. This section was harder to separate into categories because each card has an isolated question and answer. However, the *Question* cards could be grouped by the kind of information they addressed (see page 36 for complete explanation).

The complete Drawing 1 was used as the first image to be shown in this section. It is used on the cards that answer medical questions about ALS. The image below is used on the first five cards of the *Question* section.



Implementation

The second set of questions in the *Question* section addresses treatments for the disease, like drug therapy. The image used was a closer cropping of the ill man with the big hands.

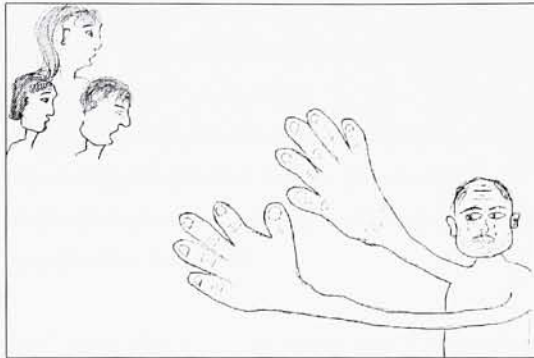


The third set of questions presents information regarding how the illness affects the body. The image of the man was enlarged again and used for this section to illustrate a level of anxiety that the patient may be feeling.



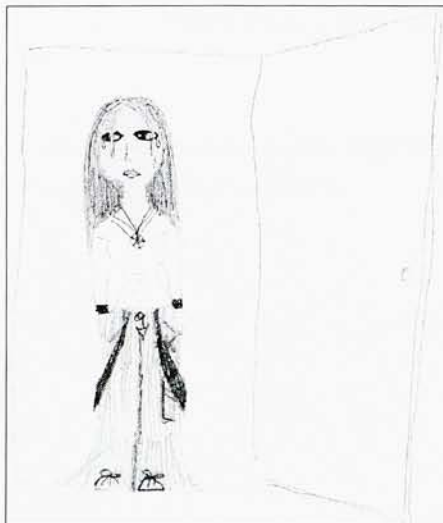
Implementation

The fourth set of questions targeted historical information about the disease including other names for the disease, and famous people who had been diagnosed with ALS. The first image used in the *Question* section was used again. However a smaller version of the image was used because the content is less serious.



Imagery for the Cope Section

Two croppings of Drawing 2 were used for the *Cope* section of the card deck. The first image was a close up of half of the girl's sad face. She is peering into the card, unsure of how to feel and what to do. This image was used for the first part of the section that discusses typical feelings and support group information. The second image used for the resource part of this section was the image of the girl standing in a doorway. This conveys a feeling of "doors being open" to those who are in need.



Missing Page

Intermediate Evaluation

The creation of the final application involved the incorporation of the feedback given by faculty, peers, and committee members. Final decisions for the card deck were developed through a series of test prints. Once all these changes were incorporated, a version of the card deck was printed and presented in the thesis exhibition. After the exhibition, the card deck was presented to committee members and the focus group for review. Thesis committee members had concerns about use of imagery. There did not seem to be enough variety from card to card. There were also concerns about the medical illustrations feeling out of place because of the way in which they were drawn. One suggestion was to include medical illustrations created in a similar manner to the other illustrations in the deck. Another suggestion was to make the illustrations more graphic with less detail.

Both suggestions were implemented. The purpose of the medical illustrations was very different than the purpose of the illustrations drawn by the teens. The medical illustrations were used to explain medical equipment and procedures. Having these illustrations drawn in a different manner made a clearer distinction between the illustrations and their purpose.

A questionnaire was developed to present to the focus group at Rush Henrietta High School to determine the effectiveness of *ALS: An Informational Card Deck* in providing information and being visually stimulating and interesting. The students were presented with two versions of *ALS: An Informational Card Deck*. They were shown the version that was presented in the exhibition at Bevier Gallery. A second set of cards that had incorporated the feedback from committee members was also presented to the teens. The revised cards implemented suggestions about the use of imagery. Students were asked if the revised deck was an improvement.

The results of the questionnaire are summarized on the next page. Completed questionnaires by the focus group are located in Appendix C.

Intermediate Evaluation

The following are the average scores from each of the questions on the survey.

1 = No, not a all. 5 = Yes, a great deal.

1. Do you thing the card deck format helps to present the information in an accessible way?	5.0
2. Do you find the colors have a calming effect?	4.8
3. Is it helpful to highlight key words and phrases in different colors?	4.8
4. Do you find the imagery interesting and appealing?	4.0
5. Do you think the card deck would promote conversation between a parent (or other adult) and a teen?	4.4
6. Does the inclusion of the Calvin & Hobbes cartoon help to make the deck more appealing and friendly?	4.6
7. Do you find the imagery in the revised deck to be an improvement?	4.8

Overall there was a positive response from the teen focus group. Question 4 received the lowest score. Some felt that the imagery could repeat less, offering more visual interest. All agreed that the imagery on the revised deck was an improvement. The imagery was darkened to make it easier to see, and the medical illustrations were made more graphic. The teens thought that the revised medical illustrations were easier to see and understand.

Most students responded well to the Calvin & Hobbes cartoon. However, one student mentioned that it seemed a little out a place and possibly inappropriate for the subject matter.

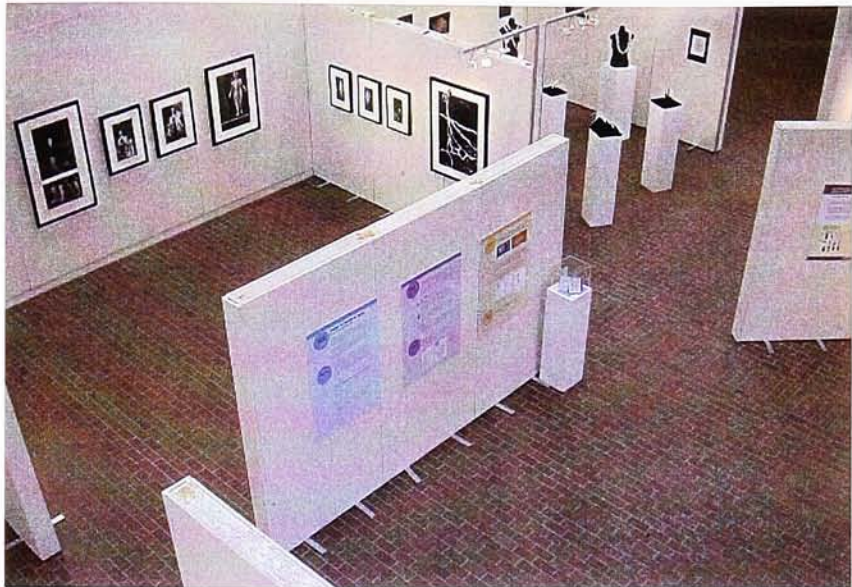
The card deck was first shared during the second 2003 thesis exhibition at the Bevier Gallery at the Rochester Institute of Technology.

Bevier Gallery Exhibit

A series of explanatory panels were designed and displayed for this exhibition. The goal of the panels was to communicate the design process that had been undertaken in the creation of the final application. The overall approach for these panels reflected the actual cards divided into three sections, each with its own color. The panels included information about processes that occurred during the project, content considerations, aesthetic decisions, and future plans for the application.

The cards were arranged and displayed on a pedestal. Several cards that best represented the goals of the application were displayed in a upright position. One card from each section was placed underneath, backside up to show what the back of the cards looked like as well. This added an element of visual interest to the display. The rest of the deck was stacked and placed inside the display to show the viewer that the cards being shown were representations of a much larger set. The exhibition display is shown on the next page.

View of thesis exhibition panels
from above the gallery



View of thesis exhibition panels
from inside the gallery.



Larger examples of the thesis panels are displayed on the next three pages.

Problem Statement

Design for Sensitive Topics Empowering the Teen

A teenager, seeking to understand a terminal disease, may find sources that are either for adults or children. The material is either presented in a way that they cannot understand, or has a childish approach. This leaves the adolescent more confused and frustrated.

This thesis developed a system of communication materials for the teenagers who may be dealing with a terminally ill parent or loved one. These materials will offer simplified information about the disease and coping methods related to the disease called Amyotrophic Lateral Sclerosis (also referred to as ALS or Lou Gehrig's Disease).

Research

Research for this project involved the exploration of information design, card deck structures and uses, Amyotrophic Lateral Sclerosis information, and understanding the needs of a teenager with a terminally ill parent or loved one. An analysis was conducted of existing materials that provide information about Amyotrophic Lateral Sclerosis. It was concluded that none of these materials were aimed toward the teenage audience. Another important branch of research was devoted to understanding how a teenager may deal emotionally with this kind of stress present in their lives.

Comparative Matrices used to Organize Research Findings

Web sites	Content: General							Point of View				Audience			
	Define ALS	Coping Skills	Research Info	Parent Care Issues	Support Group Info	FAQ ALS	ALS Research	Personal Story	Teenage	Adult	Parent	Concierge			
lybaleh.com	*	*	*	*	*	*	*	*				*	*	*	*
staleto.com	*	*	*	*	*	*	*	*				*	*	*	*
sls.org	*	*	*	*	*	*	*	*				*	*	*	*
slswork.com	*	*	*	*	*	*	*	*				*	*	*	*
slscentral.net	*	*	*	*	*	*	*	*				*	*	*	*
sls.us	*	*	*	*	*	*	*	*				*	*	*	*
slsresearch.com	*	*	*	*	*	*	*	*				*	*	*	*

ALS Basics (Title)	Content			General Audience			Specific Audience		
	Define ALS	Explain Medical Information	Inspiration	Child	Teenage	Adult	Medical Professional	Parent	Concierge
A Baseline for Young People	*	*	*	*					*
Grandpa, what is ALS?	*	*	*	*					*
Journeys with ALS	*	*	*	*		*		*	*
Tuesday's With Mom	*	*	*	*		*		*	*
Mom in His Own Words	*	*	*	*		*		*	*
Amyotrophic Lateral Sclerosis	*	*	*	*		*		*	*
Amyotrophic Lateral Sclerosis: A Guide for Patients and Families	*	*	*	*		*		*	*
ALS: 1994 and Beyond: New Hopes and Challenges	*	*	*	*		*		*	*
Motor Neuron Disease	*	*	*	*		*		*	*

Exhibition Panel 1 displayed in the
Bevier Gallery at RIT

Content

The content for the deck of cards was developed from library research, internet research, the analysis of existing materials, discussions with teenagers, and personal experience. Information was chosen that would help the teenager understand the terminal illness, and anticipate the course of events as the disease progresses. The goal is for this knowledge to help reduce fear and anxiety about the unknown and unexpected. The Deck of cards was divided into three main sections: Know, Question and Cope.

Three Identified Sections

Know

This section provides medical facts about ALS. It defines what the illness is, how it affects the body, what the symptoms are, life support equipment and procedures and current research to find treatment and a cure. By fully understanding the nature of the illness, the teen can prepare themselves for what is to come.

Question

This section of the deck provides answers to the most frequently asked Questions about the disease with a brief but descriptive answer. The questions are laid out in a table of contents, allowing the viewer to read them all and decide which question they would like the answer to.

Cope

This section contains information that may help the teenager expect and cope with various kinds of feelings due to a parent having ALS. The goal of the Cope section is to offer information about support groups, encourage teens to ask questions and to talk about their feelings with someone they trust.

Structure

The cards were designed to allow small amounts of information to be uncovered at a time, in the hopes that it would not overwhelm the viewer. The card deck can also be used as a tool to promote conversation between parent (or adult) and teenager.

Know

1. Defining Amyotrophic Lateral Sclerosis (ALS)
2. I Still Don't Understand ALS
3. What ALS Needs For
4. What's Happening Here
5. Symptoms
6. Treatment
7. Drug Treatment
8. Exercise
9. Getting Around
10. Assisted Breathing
11. Life Feeding
12. Assisted Feeding Options
13. The Assisted Breathing
14. Homecare Ventilation
15. Homecare Ventilation

Know

Amyotrophic Lateral Sclerosis (ALS), often referred to as "Lou Gehrig's Disease," is a disease that attacks nerve cells in the brain and the spinal cord. Nerve impulses travel from the brain to the spinal cord and from the spinal cord to the muscles throughout the body. The progressive degeneration of the motor neurons in ALS eventually leads to their death. When the motor neurons die, the ability of the brain to initiate and control muscle movement is lost. 100% of voluntary muscle action affected patients in the later stages of the disease become totally paralyzed. Not enough is all for the majority of people. Their muscle disease progresses.

A Table of Contents and tabbing system were created to make it easy for the viewer to find information within the cards. Color is also used to identify each section.

Exhibition panel 2 displayed in the Bevier Gallery at RIT

Aesthetics

This card deck was created with a teenage audience in mind. The cards needed to be visually appealing, and respective of the sensitive subject matter. Popular teenage card games and magazines were collected and analyzed as influences on design decisions.



Pages from popular teenage magazines



Various card games and decks

A distinct color was chosen to denote each section of the cards. A light blue was chosen for its calming effect and was used for the Know section of the cards. Purple was chosen for the Question section of the cards because of its association with power. Peach was chosen for the Cope section because of its nurturing and cheerful quality.

In a quest to understand the teen audience a focus group was created to participate in the project by filling out a survey and creating illustrations that could be used as imagery on the cards. Graphic elements, colored type and lively colors were also used as the means to stimulate the audience and make the cards friendly and appealing to use.



Illustration by
Nazan Koksal

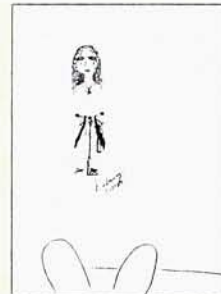


Illustration by
Dina Katawazi

Future Progress

This version of the card deck is a work in progress that will continue to develop in the months ahead. The project will be disseminated to a focus group of teenagers for evaluation.

Exhibition Panel 3 displayed in the
Bevier Gallery at RIT.

Future Dissemination Plans

In the future, the *ALS: An Informational Card Deck* could be mass produced and distributed through different channels. The card deck could become part of the ALS Society of Canada's materials distributed to patients and families. Neurologists could use the card deck as a guide to help explain the disease to a teen audience, and might even want to pass the deck on to interested parties. ALS Centers around the country may find it useful to have the card deck as part of the permanent collection in their medical library. Public Libraries may also wish to have the deck as a reference material within their collection.

The *ALS: An Informational Card Deck* may be too expensive for a non-profit organization, like the ALS Society, to produce. The card deck could be converted into a two color solution using various shades of one of the three colors and black to cut down on the cost of printing.

Public use of the cards, like in a public library, or medical library, where many persons are handling the cards, makes them more vulnerable to being lost or damaged, making them unusable after a long period of time. A solution would be to have the cards bound in one corner with a pin, to make the deck less susceptible to lost cards.

A web site could also be created in addition to *ALS: An Informational Card Deck*, and would contain similar information. This would allow people to access the information if they could not get the actual deck. Information in the web site could be updated quicker and more efficiently than in the card desk.

ALS: An Informational Card Deck successfully offers information to the teen audience in a understandable and accessible manner. The color palette establishes a calm and welcoming feeling to the reader. The highlighted key words and phrases help the reader see the most important information on the card at a quick glance.

The use of imagery provided visual interest, an emotional connection between the material and the reader, and attempted to subtly connect cards with a similar topic together as a set. Although teens seemed to respond well to the imagery, it was noted that there could be less repetition of the imagery to offer more interest. It was also noted that the imagery didn't necessarily fit the context of the information on some of the cards, specifically in the *Question* section. This could be solved by hiring an illustrator to create images specifically relating to the information on each card. This would also provide a stronger connection between the information and the image.

The card deck offers plenty of information to the teen audience regarding factual information about the disease. However, more resources and information could be included in the *Cope* section of *ALS: An Informational Card Deck*.

The small and intimate format of the card deck was well received as a way to promote conversation between a parent and child. Some teens felt that conversation is hard enough, but the deck was a vehicle to get two people talking. Teens felt that the information in the deck was so accessible and vast, that an adult explanation or conversation would not be necessary. The cards could be used by the teen themselves. *ALS: An Informational Card Deck* was successful in achieving both goals as a conversation stimulant and as a tool providing accessible information for the teen to use on their own.

The Calvin & Hobbes comic strip provided some relief from all of the serious information. However, this cartoon may be somewhat inappropriate for the subject matter. Perhaps there is a better comic strip that could be incorporated with the cards. Another option would be to create a comic strip specifically for the card deck.

Conclusion

The teenage audience is often forgotten when materials are developed about terminal illnesses. Materials are written for the adult audience and young children. However, the teen, caught between childhood and adulthood, is often left having to read materials that were never intended to address their mental and emotional needs.

ALS is a disease that has little written about it, and nothing directed to the teenage audience. Resources that are available are either very dense and hard to understand, or do not provide enough information. This thesis project attempted to present thorough but accessible information about a terminal illness and coping methods to a teen audience.

The development of *ALS: An Informational Card Deck* involved research, synthesis, ideation, implementation, and dissemination. The designer learned to develop diagrams and matrices as a means to organize and identify useful research findings to generate design solutions. The incorporation of all of these stages of design process into the project has successfully developed an important information and emotional guide for teenagers coping with a terminally ill parent.

ALS: An Informational Card Deck addresses the intellectual, emotional, and visual needs of a teenager struggling with the stress of a terminally ill parent. The information was presented in an interesting and accessible way. Teens found that they related well to the use of colors, and the color palette was soothing and comforting. Highlighted text made it easier to see and understand key words and phrases. Students commented that it is difficult to discuss sensitive topics. However, they found the smaller format useful in promoting a conversation with an adult.

This thesis project allowed the designer to increase knowledge and understanding about information design, systems design, typography, and color theory. The designer combined prior knowledge in these areas as well as new, additional research to successfully develop *ALS: An Informational Card Deck*.

Conclusion

The designer of *ALS: An Informational Card Deck* has gained an increased knowledge and understanding of the emotional and intellectual needs of a teenager, the importance of information materials that address needs unique to this age group, and the use of design to create meaningful and visually interesting solutions for the teenage audience. It is a complex and challenging process to develop graphic design solutions that both visually stimulate the viewer and are sensitive to the serious subject matter. It is the responsibility of designers to recognize and overcome this challenge and provide materials for teenagers that they can relate to. Providing these materials will reduce information anxiety and enable teens to cope with the stresses in their lives.

Glossary of Terms

Amyotrophic Lateral Sclerosis (ALS)	Also known as Lou Gehrig's Disease, a progressive and fatal neuromuscular disease.
Focus Group	A group of people who fit the profile of the audience you are trying to reach. This group participates in the project as a means of offering research and feedback on the success of the project.
Forced Juxtaposition	A brainstorming method that encourage, or forces making connections between attributes of a subject that may not otherwise have been done.
Leading	The spacing between lines of text.
Lou Gehrig	Famous baseball player that died from ALS. Lou Gehrig's Disease is a common layman's term for ALS in the United States.
Neuromuscular	Of or relation to nerves and muscles; jointly involving nervous and muscular elements.
Dissemination	Plans for audience interaction; distribution.
Ideation	The generation of a conceptual solution and preparation of a range of preliminary design approaches.
Information Design	The defining, planning and shaping of the contents of a message and the environments in which it is presented, to achieve particular objectives in relation to the needs of the users.
Implementation	Description of how the project was refined, developed and produced to its final form or application.
Matrix	A rectangular arrangement of elements into rows and columns. A comparative matrix can be used as a tool for organizing or comparing information or research.
Mind Map	A brainstorming method used to discover new ideas. Mind maps begin with a central word or node, and other words or ideas are written around, branching out from the central node.

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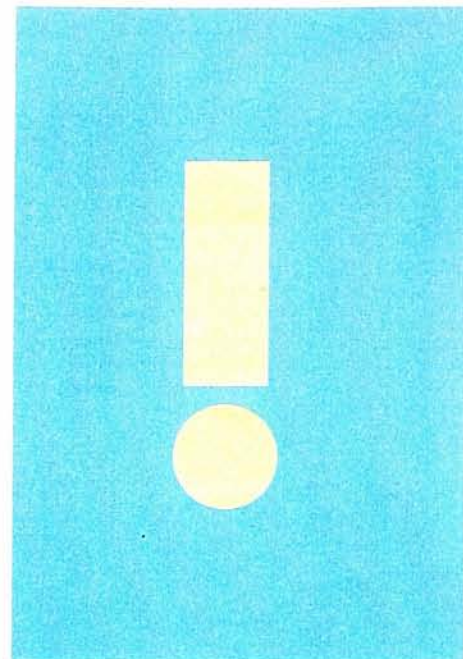
Appendix A Complete Design Application

Full card deck represented at smaller scale.

Know

Table of Contents

- 1 Defining Amyotrophic Lateral Sclerosis (ALS)
- 2 I Still Don't Understand ALS
- 3 What ALS Stands For
- 4 Please Explain More
- 6 Symptoms
- 7 Treatment
- 8 Drug Treatment
- 9 Exercises
- 10 Getting Around
- 11 Assisted Eating
- 12-13 Tube Feeding
- 14 Assisted Breathing Options
- 15 No Assisted Breathing
- 16 Noninvasive Ventilation
- 17-18 Invasive Ventilation



Know

Calvin and Hobbes



by Bill Watterson

Know

Defining ALS

Amyotrophic Lateral Sclerosis (ALS), often referred to as "Lou Gehrig's Disease," is a disease that attacks nerve cells in the brain and the spinal cord. Motor Neurons reach from the brain to the spinal cord and from the spinal cord to the muscles throughout the body. The progressive degeneration of the motor neurons in ALS eventually lead to their death. When the motor neurons die, the ability of the brain to initiate and control muscle movement is lost. With all voluntary muscle action affected, patients in the later stages of the disease become totally paralyzed. Yet, through it all, for the vast majority of people, their minds remain unaffected.



Know

I Still Don't Understand ALS!

Muscle movements are controlled by the brain. The brain tells the muscles what to do by sending them messages. The brain needs help to do this and relies on nerves to carry messages to the muscles. These nerves are called *Motor Neurons*.

When someone has ALS, something goes wrong with their *Motor Neurons*. They are unable to get messages through, so the muscles will not move properly. If messages do not get through, the muscles will gradually not be able to move at all, no matter how hard the person tries.



Know

What does ALS Stand For?

*Am*yo*tr*o*phic* *L*ateral *S*clerosis:

A = absence of
myo = muscle
trophic = nourishment
Lateral = side (of spine)
Sclerosis = hardening



Know

Please Explain More

A-my-o-trophic comes from the Greek language. "A" means no or negative. "myo" refers to muscle, and "trophic" means nourishment = "No muscle nourishment." When a muscle has no nourishment, it "atrophies" or wastes away. "Lateral" identifies the areas in a person's spinal cord where portions of the nerve cells that nourish the muscles are located. As this area degenerates it leads to scarring or hardening ("Sclerosis") in the region.



Know

Symptoms

At the onset of ALS the symptoms may be so slight that they are frequently overlooked. With regard to the appearance of symptoms and the progression of the illness, the course of the disease may include some or all of these symptoms.

- Muscle weakness in hands, arms, legs or the muscles of speech, swallowing or breathing
- Twitching and cramping of muscles, especially those in the hands and feet
- Impairment of the use of the arms and legs
- Projecting the voice becomes difficult.

Shortness of breath, difficulty in breathing and swallowing appear in more advanced stages of the illness.



Know

Treatment

Even though there is no cure for ALS yet, there are *effective treatments* to help the patient live with the disease. Sustaining the highest level of function and comfort is an important goal in the management of patients with ALS.

Drug Treatment
Exercise
Getting Around
Assisted Eating
Assisted Breathing



Know

Drug Treatment

Riluzole - Rilutek™ is the first and only drug to receive FDA approval for the treatment of ALS. Clinical trials in America and Europe have shown that Riluzole significantly slows the progression of the disease.



Know

Exercises

There are no exercises that will stop or slow the progression of the disease. However exercises—including breathing exercises—will strengthen unaffected or less affected muscles. These exercises are not vigorous or tiring, but are intended to help maintain mobility and prevent joint stiffness and muscle contracture.



Know

Getting Around

Various devices such as foot-drop braces, hand splints, limb supports or wheelchairs enable the patient to remain as independent as possible.



Know

Assisted Eating

10

Eating may become hard or dangerous for the patient to do because of difficulty with chewing, swallowing, or moving food around in their mouth.

Tube feeding provides a practical option for those individuals who are unable to meet their nutritional needs by mouth. With tube feeding the source of food is in liquid form. Tube feeding formulas provide all the nutrients found in a well-balanced diet.



Know

Tube Feeding Procedure

11

There are several types of tube feeding. The most commonly prescribed tube feeding for patients with ALS is Percutaneous Endoscopic Gastrostomy, often referred to as a PEG.

The tube is placed directly into the stomach through an incision in the outside of the abdominal wall.



Know

Tube Feeding Procedures

12

The tube can easily be kept out of sight when not in use and generally do not cause physical discomfort or irritation after the incision has healed.

Nutrient dense liquid is then put into a bag, and hung from a hook, much like an IV bag. The machine helps to move the liquid through the tube.



Know

Assisted Breathing Options

13

As ALS progresses, it will eventually affect the patient's ability to breathe on their own. There are a few options available to the patient as they are faced with respiratory muscle decline. The options are listed on the following cards.

14 15 16 17



Know

No Assisted Breathing

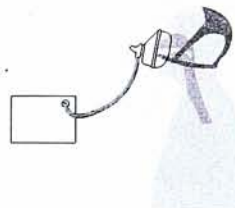
The first option is having **no mechanical support**. This option is best combined with symptom relief through medications and emotional support. However, failing or ineffective respiration will be fatal.



Know

Noninvasive Ventilation

Noninvasive ventilation means that there is **external breathing assistance** either through a face mask as shown below, oral appliances, or nasal pillar connected to a small ventilator is more commonly used. They are used on and off, mostly at night, and may not provide enough assistance for a patient with very poor muscle strength in lungs and/or mouth.



Know

Invasive Ventilation

Invasive ventilation is conducted with the placement of a tracheostomy tube directly into the neck and airway through an incision. The tube consists of a curved round tube with an outer cannula, an inner cannula and a flange. A small balloon device surrounds the end of the tube, which reside in the airway to form a seal that permits ventilation. Air can no longer pass over the vocal cords, so the patient will be unable to speak.



Know

Invasive Ventilation

A vent is then hooked up the outer cannula which allows high pressure ventilation to occur, completely supporting the breathing needs of the patient.



Question

Table of Contents

- 18 What is ALS?
- 19 What causes ALS?
- 20 How is ALS diagnosed?
- 21 Who gets ALS?
- 22 Is there a cure for ALS?
- 23 What treatments are available?
- 24 Are there any new, promising treatments for ALS?
- 25 Is ALS painful?
- 26 Is ALS contagious?
- 27 Is ALS hereditary?
- 28 How long do people with ALS live?
- 29 Does ALS affect the mind?
- 30 Are there other names for ALS?
- 31-32 Are there any famous people with ALS?



Question

Calvin and Hobbes



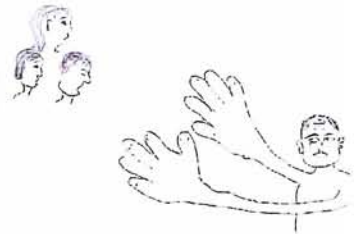
by Bill Watterson

Question

What is ALS?

18

ALS is a fatal **neurodegenerative disease** characterized by progressive muscle weakness resulting in paralysis.

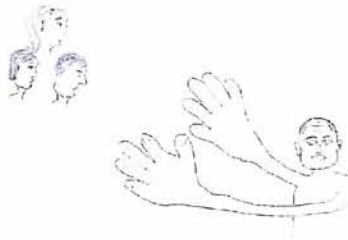


? Question

What causes ALS?

19

The cause of ALS is unknown. Researchers know that an excess of a neurotransmitter called **acetylcholine** clogs the synapse of the nerve cell preventing transmission of neural impulses. The cause of this neurotransmitter **acetylcholine** **acetylcholine** **acetylcholine** although there are several theories being developed.

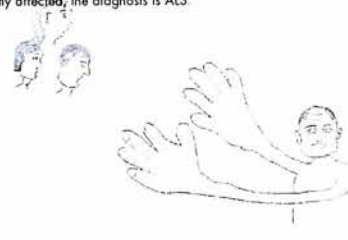


? Question

How is ALS diagnosed?

20

ALS is diagnosed through a process of elimination and may take several months. Early ALS symptoms may be similar to a number of other neuromuscular diseases. Diagnostic tests include **EMG** (Magnetic Resonance Imaging), **EMG** (Electromyogram), **EMG** **EMG** **EMG** and **EMG** **EMG** **EMG**. In order for a definitive diagnosis of ALS to be made, damage must be evident in both upper and lower motor neurons. When three limbs are sufficiently affected, the diagnosis is ALS.

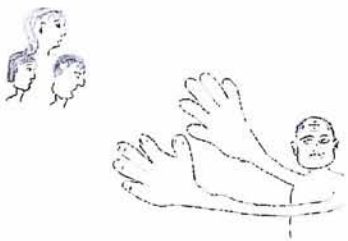


? Question

Who gets ALS?

21

ALS occurs in both sexes and all races. Men are much more likely to get ALS than women. Older people are more likely to get ALS than younger people. ALS is most common in people between **ages 40-70**.



? Question

Is there a cure for ALS?

22

There is **no cure** for ALS, but there is a great deal of promising research going on now.





Question

What treatments are available?

23

There is one FDA approved drug, **Rivastigmine**, which slows progression of the disease. There are a number of other medications to help relieve symptoms of ALS. Therapies, supplements, and proper nutrition can be part of a treatment plan.



Question

Are there any new, promising treatments for ALS?

24

Yes, due to the quantity of ALS research going on now, new potential treatments are being discovered on a regular basis. An example of a promising new treatment is the over-the-counter supplement called **Creatine**. Recently, Creatine was shown to be effective in preventing ALS in studies on mice.



Question

Is ALS painful?

25

The motor neuron damage and muscle atrophy caused by ALS is not painful. **Some of the effects** of ALS may be painful. Common pains as a result of ALS include pressure sores, muscle cramps, joint contractures, constipation, burning eyes, swelling feet, and muscle aches.



Question

Is ALS contagious?

26

ALS is **not** contagious. You cannot catch it from hugging, kissing or by being in the same room with an ALS patient.





Question

Is ALS hereditary?

27

At least 10% of ALS cases are hereditary. This is called **Familial ALS**. Generally, we define Familial ALS as two or more cases in the same bloodline. In Familial ALS, if a parent has ALS, their children have a 50% chance of inheriting the defective gene. While the risk of inheriting the defective gene is 50% for each child of an affected person, not all people with the defective gene will develop the disorder. 90% of ALS cases have no familial link, and they are called **Sporadic ALS**.



Question

Does ALS affect the mind?

28

ALS does not affect the mind! There have been some cases where ALS patients have experienced dementia, but it is unknown whether ALS was the cause of the dementia. In most cases, even when the patient is totally paralyzed, the mind functions normally.



Question

How long do people with ALS live?

29

Doctors won't be able to tell you for sure how long the person diagnosed will live, but statistics show that 50% of ALS patients die within 18 months after diagnosis. Only 20% survive 5 years and 10% live longer than 10 years. Persons with ALS who go on a ventilator may live for many years. **Integrated Healthcare** is allowing ALS patients to live longer than ever before.

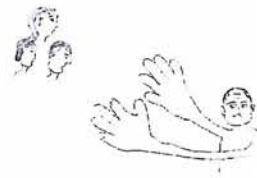


Question

Are there other names for ALS?

30

You may have already heard ALS referred to as **Lou Gehrig's Disease**, especially if you live in the United States. In England it is known as MND, **Muscle Neurone Disease**. The French refer to ALS as **Maladie de Charcot**, after the first physician to diagnose and name the disease.



? Question

Are there any famous people who have or had ALS?

31

Lou Gehrig is probably the most famous person associated with ALS, and the disease is commonly referred to by his name in the United States. He played baseball for the NY Yankees until he was diagnosed in 1939 at the age of 38.

The most famous person living with ALS is noted British physicist **Stephen Hawking**. He has been living with ALS for more than 35 years. He is able to move only two fingers. More on card 32



? Question

Are there any famous people who have or had ALS?

32

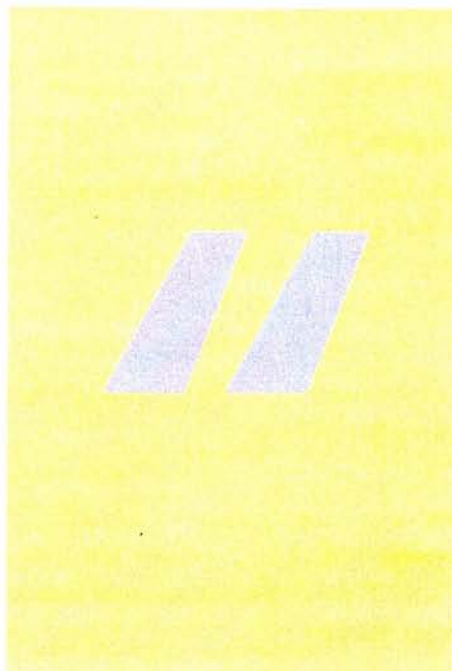
Other notable people who have had ALS are actor **David Niven**, baseball player **Carlton Fisk**, U.S. Senator **Joseph P. Kamp** and soap opera star **Michael Zaslow**.



Cope

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- 33 Introduction
- 34 Typical Feelings
- 35 Support Group Information
- 36 Resources
- 37 Journeys with ALS
- 38 Tuesdays with Morrie
- 39 Straight Talk About Death for Teenagers
- 40 A Booklet for Young People



Cope

Calvin and Hobbes



by Bill Watterson

Cope

Introduction

Coping with a terminal illness such as ALS can become quite emotionally draining for people with ALS and their families. It is a disease that affects the entire family, not just the person who is ill.

The ALS Center's team of caregivers is willing to listen to the concerns of people with ALS and their families. Social workers are just one part of the care-giving team who can offer treatment in a compassionate setting.



Cope

Typical Feelings

Anger, helplessness, fear, hope, and despair are commonly experienced. You are entitled to have these feelings, so do not be ashamed of them. Everyone experiences some or all of these feelings at some point in time. You may also experience feelings like:

- Curiosity
- Love
- Disbelief
- Loss
- Anticipatory grief
- Guilt
- Erosion of trust
- Denial
- Responsibility
- Persistence
- Sadness
- Loneliness
- Jealousy
- Annoyance
- Feeling trapped
- Feeling overwhelmed



Cope

Support Group Information

Sometimes talking with someone that is experiencing a similar situation can be very comforting.

Support groups allow people to come together to share the common experiences and problems unique to their situation.

Information on support groups in your area can be found in a variety of ways. Handbooks of community resources, including support groups, are usually available in local libraries and hospitals. Major groups are often listed in the Yellow pages under "social service agencies".



Cope

Resources

The next few cards in the deck are a list of book resources that provide information and stories about coming to terms with a loved one's illness and eventual death. A brief description about the book is included on the card.



Cope

Journeys with ALS

Compiled by David Feigenbaum (ALS patient)
DLRC Press
P.O. Box 61661
Virginia Beach, VA 23466
Published 1998
(757) 473-1130 or 1-800-776-0560
ISBN 1-880731-58-4/Soft cover

In this book you will find 33 first-person journeys with ALS. Some are hopeful, some sad. A few are angry. All are powerful, real-life examples of people doing their best to cope, often with humor and high spirits.

